

SUPPORTING AUTISTIC ADULTS IN ACHIEVING OCCUPATIONAL PERFORMANCE

Teal W. Benevides, PhD, MS, OTR/L

Associate Professor

Augusta University

Stephen M. Shore, EdD

Clinical Assistant Professor

Adelphi University

South Carolina Occupational Therapy Association

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Disclosure of Conflicts of Interest



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- The views presented in this presentation are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors, or Methodology Committee.
- Teal Benevides & Stephen Shore declare no financial conflicts of interest with entities who paid for the study.
- Portions of this presentation have been presented elsewhere, and the following publications describe aspects of this project:
 - Shore, S., Benevides, T.W. and AASET Community Council. Engagement and Compensation Guide, Ver. December 2018. Available at: <https://www.pcori.org/sites/default/files/AASET-Engagement-Guide-122018.pdf>
 - Benevides, T.W., Shore, S. and the AASET Community Council (in press). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism (Special Issue in Mental Health)*.doi: 10.1177/1362361320908410
 - Benevides, T.W., Shore, S. and the AASET Community Council (in press). Interventions to Address Health Outcomes Among Autistic Adults: A Systematic Review. *Autism*.

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Stephen's Story

**"If you've met
one individual
with autism,
you've met one
individual with
autism."**

- Stephen M. Shore



Stephen Shore intro

Objectives

At the conclusion of this presentation, learners will:

1. **Identify** 3 specific actions that support authentic alliance with autistic adults.
2. **Discuss** opportunities for promoting increased quality of life and occupational performance, aligned with priorities that are identified by this population.
3. **Promote** practice with individuals, groups, and populations through case evaluations.
4. **Interpret** evidence that supports authentic alliance with autistic adults.

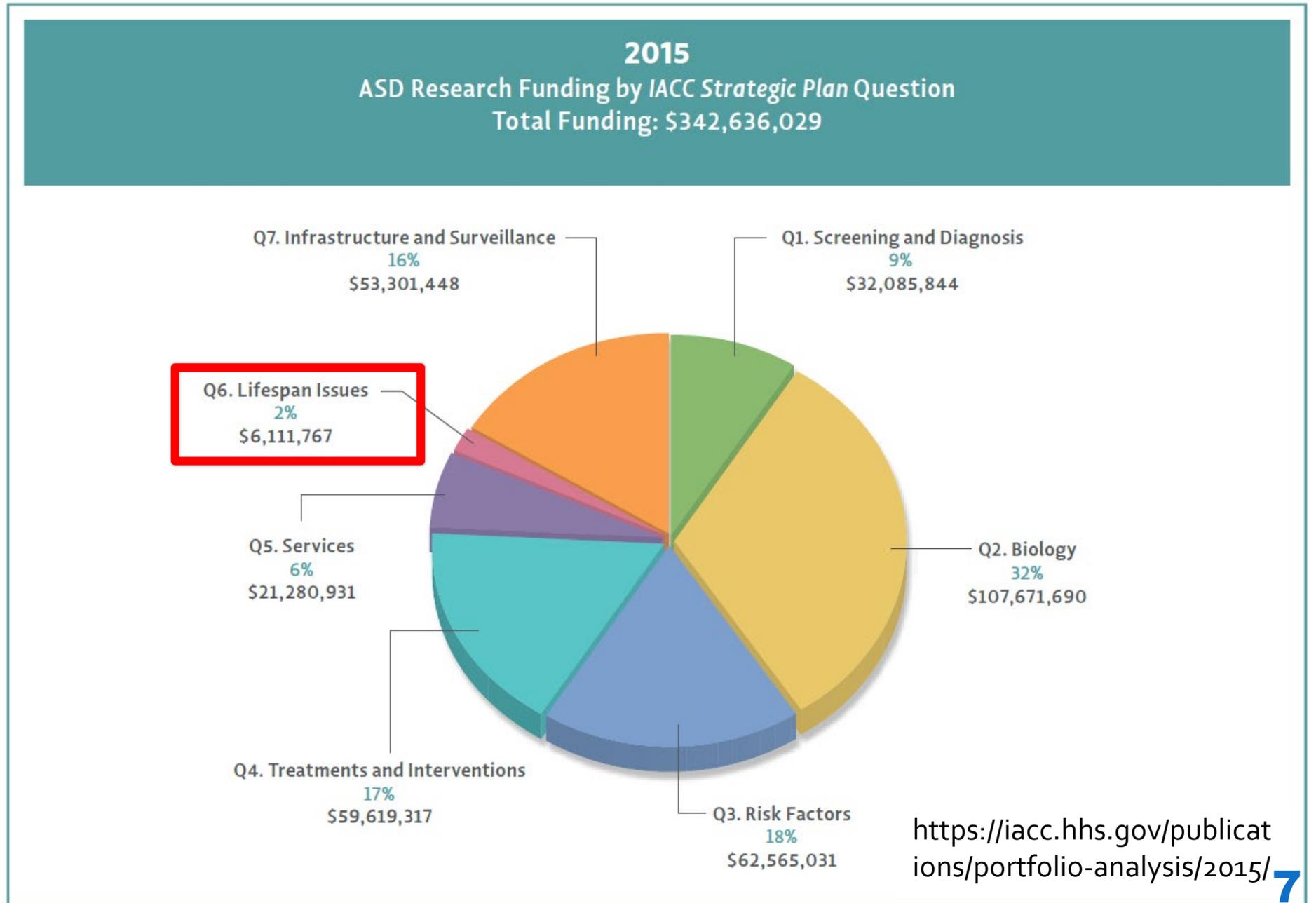
Why Is It Important to Talk about Autistic Adults in Occupational Therapy Practice?



Why is it important to talk...



Autistic adults have multiple, chronic, and potentially preventable healthcare needs as compared to same-aged adults without ASD.



Fundamental Need to Ensure Autistic Individuals are Involved in Setting Priorities for Research & Practice

- Pellicano et al. (2014) reported on priorities from within U.K., as shared by:
 - 122 autistic adults
 - 849 immediate family members
 - 426 professionals
 - 120 researchers
- Gaps exist:
 - Priorities of the adult community have not been comprehensively sought and systematically addressed in the U.S.
 - Practitioners, researchers, funders, organizations, and others may benefit from knowledge about how to best engage with the adult community in collaborative ways.

Funded by PCORI to Accomplish the Project Goals

- To meaningfully include and engage autistic stakeholders in answering the following questions, in preparation for a patient-centered outcomes research CER study:
 1. What are the health research priorities as identified by autistic adults?
 2. What preferences for engagement and methods are successful when incorporating autistic adults as researchers in the research process?



AASET

Autistic Addults and other Stakeholders Engage Together

Participatory Action Research Design

- Established a Project Team comprised of autistic and non-autistic individuals



Teal Benevides

Project Lead



Stephen Shore

Project Co-Lead



Alex Plank

Social Media Coordinator



Patricia Duncan

Meeting Planner

- Established a paid Community Council of autistic adults and other stakeholders to inform and guide patient-centered outcomes research
- 18 Community Council members joined and contributed
- Bios and info available at www.autistichhealth.org
- Involved other stakeholder individuals and organizations in priority-setting

Involvement of the Community in All Steps

- The Community Council was paid for their involvement as an equal partner.
- All actions during the project were planned, discussed, reviewed and ultimately approved by the Community Council.
- All questions for surveys and focus groups were trialed, revised, and reviewed by the Community Council.
- All consent forms, flyers, and meeting documents were reviewed, revised, and approved by the Community Council.



Why we
paid our
community
council

Approximately 400 people engaged with us over 2 years

- Participatory action research approaches 1/1/2017-12/31/2018
 - Large group stakeholder meetings
 - July 2017 (n=51)
 - November 2018 (n=64)
- Online survey of autistic adults, launched Aug 2018 (n=249)
- Face-to-face focus groups of autistic adults Aug-Nov 2018 (n=26)

An Invitation Today to Consider Your Role...

Occupational therapy practitioners are called to focus on the following Vision 2025

As an **inclusive** profession, occupational therapy maximizes health, well-being, and quality of life for all people, populations, and communities through effective solutions that facilitate participation in everyday living.

Principles of Engagement for Authentic Alliance

1. Presume Competence
2. Use Respectful Language
3. Appropriate and Clear Communication is a Right
4. *Compensation and Recognition*

Respectful engagement occurs when the individual is:

- Not a token—when doing work that matched skill level for something that was a part of their expertise (not underemployment);
- Paid at the skill level they demonstrate;
- Able to give feedback on research activities and when their feedback is given equal weight as other collaborators;
- Provided work and expectations which are the same as others in that research role

From the “AASET Engagement and Compensation Guide” edited by Stephen Shore and Teal Benevides (2018), authored by the editors and the AASET Community Council

Presume Competence in All Interactions

- There is a belief in our society that individuals who do not speak are less intelligent than those who do.
 - Leads to taking away opportunities for choices, opportunities for communication.
- There is also a belief that those who do not have expressive language also do not have receptive language.
 - Leads to speaking about individuals in front of them.
 - Leads to taking away rights to communicate.



Engagement Guide
– Presumption of
competence

Use Respectful Language



Identity vs
person first
language

- **Person-first**
 - “Person with autism”
 - “Adult with autism spectrum disorder”
 - “Adult on the spectrum”
- **Identity-first**
 - “Autistic adult”
- **Known differences between preferences of autistic adults and caregivers (Kenny et al., 2016)**
- **It is appropriate to ask what a person prefers, but not to assume**

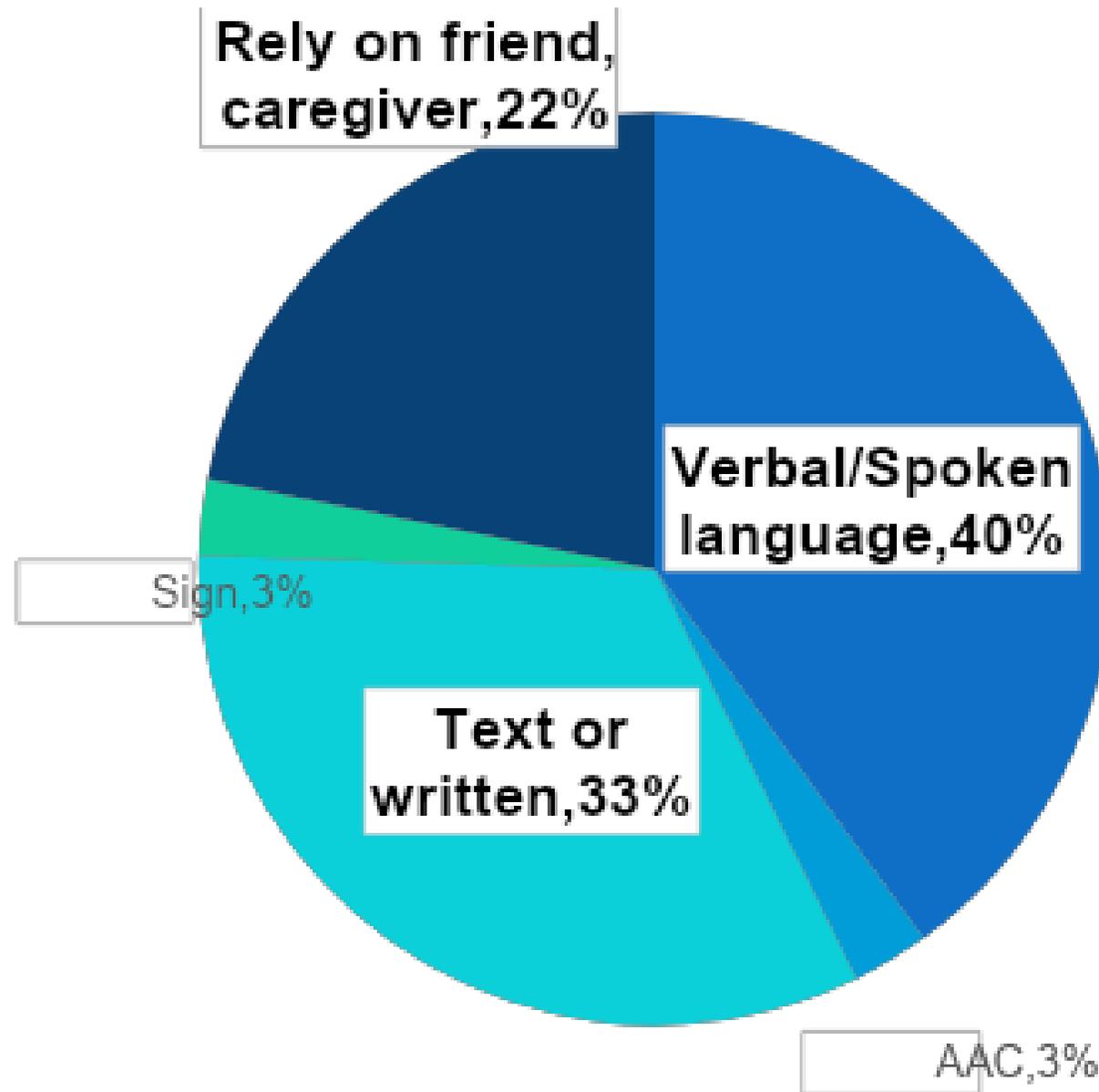
1. Gernsbacher MA (2017). Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58(7), 859-861.
2. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.
3. Sinclair J. (1999). Why I dislike "person first" language. http://web.archive.org/web/20080616063934/http://web.syr.edu/~jisincla/person_first.htm
4. *Autism in Adulthood* author guidelines require identity-first

Use Respectful Language - Other Examples

- “Non-speaking” is different than “Non-verbal”
- “Sensory differences” is better than “Sensory dysfunction”
- “Co-occurring conditions” is better than “Comorbid conditions”

Appropriate and Clear Communication is a Right

- Understand the “Communication Bill of Rights”
 - <https://www.asha.org/uploadedfiles/njc-communication-bill-rights.pdf>
- Identification of preferences for communication
- Recognition that communication preferences change
- Using best practice principles in communication
- Recognize that some phrases and turns of speech may be misunderstood
- Email structure and template may be helpful



What is your preferred way of communicating with others in a stressful situation?

Benevides, Shore, & AASET Community Council (unpublished)

Communicating through text-based approaches is good practice

- Email, text messaging, and other text/chat are good strategies to allow people the opportunity to read and re-read as needed. Processing time is allowed with text based approaches.
- Email should be structured consistently and clearly.



Communication

Example Email from the **Engagement Guide**

Purposes of the Email:

- To share results of the Year 1 meeting
- To request feedback on Conference Summary (short, 3 page summary)

Details:

- The Project Team would like feedback on the Year 1 meeting results so that we can provide to the autism community, researchers, organizations, etc.
- We will incorporate feedback from the Community Council prior to sharing with the attendees of the year 1 meeting or posting on Facebook and AASET website.

Questions include:

- Are the materials written in a way that is understandable? Clear? Respectful?
- Is there anything missing that you would want to know?

Actions:

- Read the Conference summary
- Use track changes to share edits or comments on the content of the summary
- Send feedback to sampleperson@emai.com

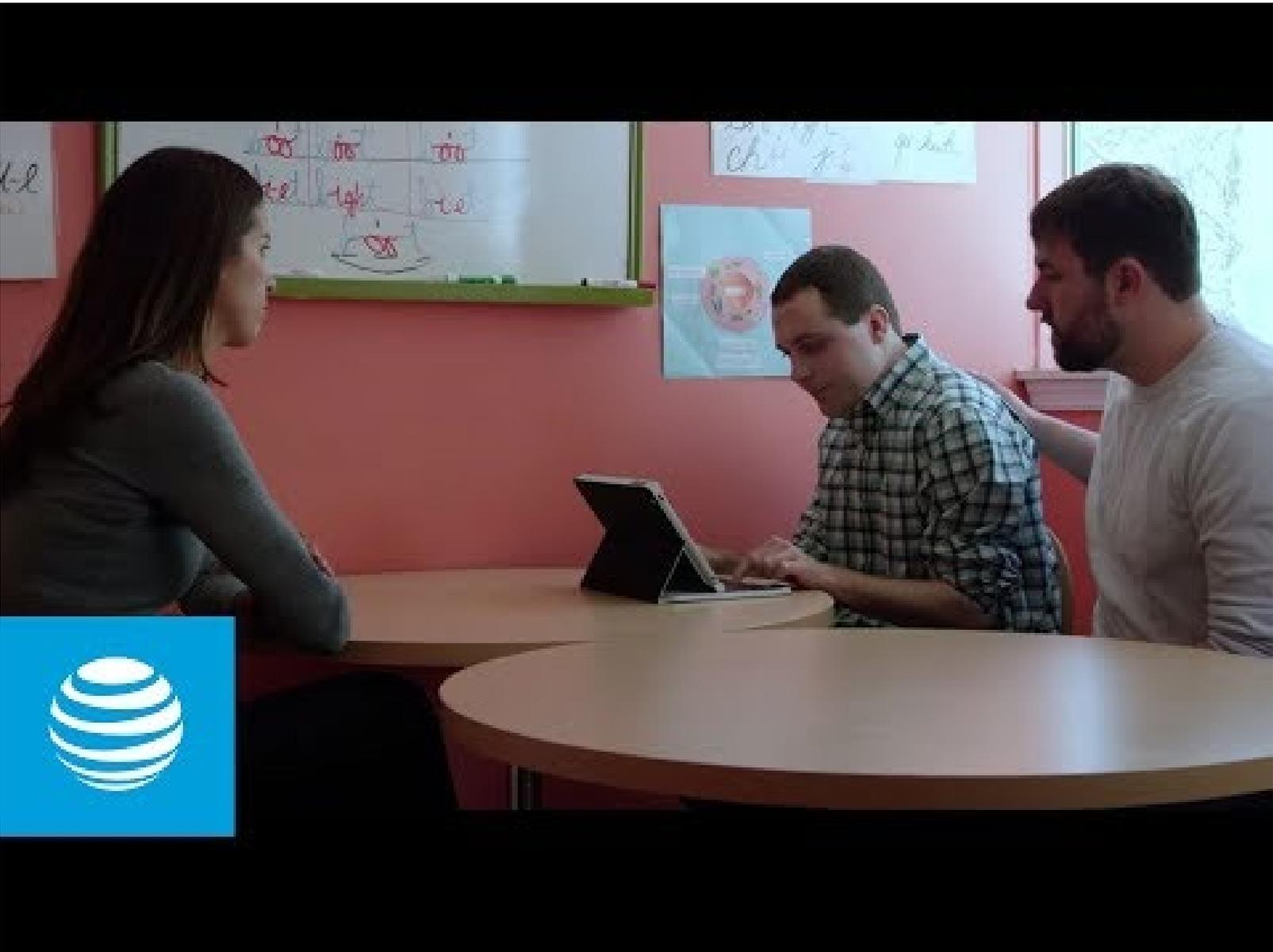
Deadline: Wednesday October 4, 2017 at 5pm Eastern Time

Template developed by Elesia Ashkenazy

Applications for Improved Communication

- Consulting with a SLP is best practice, but autistic adults report using the following apps
- **Proloquo4Text**
<https://www.assistiveware.com/products/proloquo4text>
- **FlipWriter**
<https://www.flipwriteraac.org/>
- **Emergency Chat**
https://play.google.com/store/apps/details?id=com.jeroendebusser.aspiemeltdown&hl=en_US
- **Autistic Space Kit**
<http://www.autisticspacekit.co.uk/>
- **Verbally for iPad**
<http://verballyapp.com/>

Watch Paul Kotler discuss communication



References

- Zisk, A.H. & Dalton, E. (2019). Augmentative and Alternative Communication for Speaking Autistic Adults: Overview and Recommendations. *Autism in Adulthood*. Online Ahead of Print (March 13, 2019), <http://doi.org/10.1089/aut.2018.0007>
- <https://www.liebertpub.com/doi/abs/10.1089/aut.2018.0007>
- Holyfield C, Drager KD, Kremkow JM, Light J. (2017). Systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder. *Augmentative and Alternative Communication*, 33(4), 201-212.

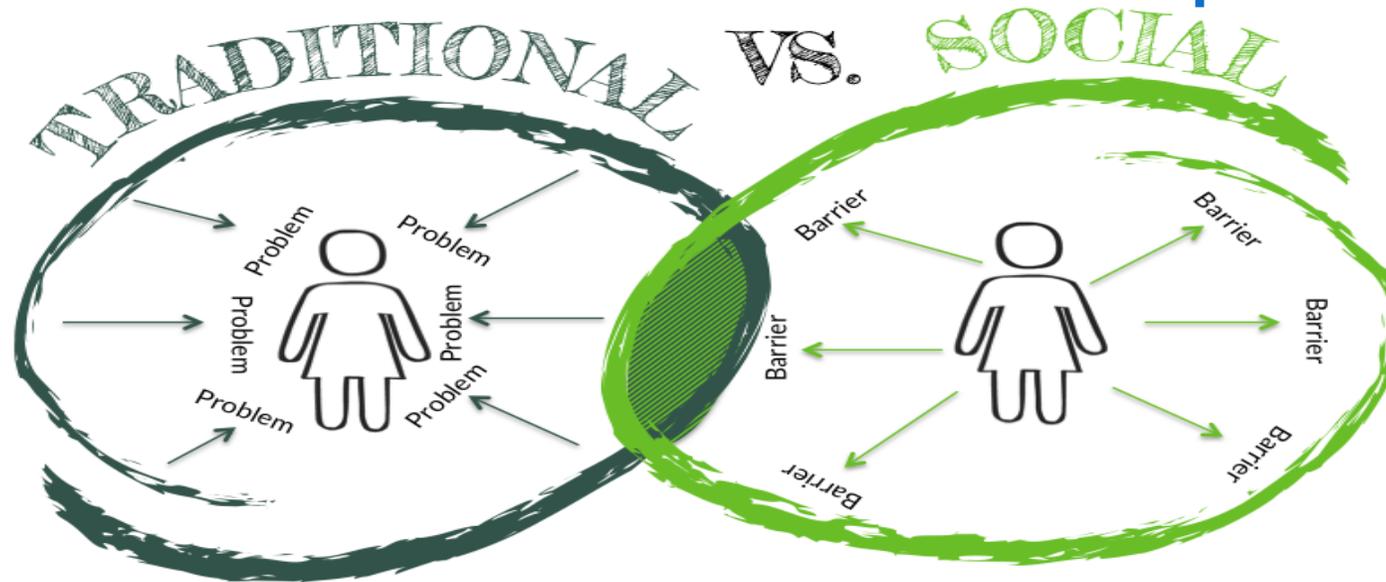
Name specific interventions that are used with individuals on the autism spectrum

- Ayres' Sensory Integration ®
- PECS
- Social Stories ™
- Sensory stimulation
- Vocational training
- Task-based practice for ADL or IADL
- Play-based interventions



Image from: www.friendsofasi.org

Where do we focus our efforts in working with individuals on the autism spectrum?



Improve sensory processing AKA "Sensory dysfunction"

Reduce "Repetitive behaviors & restricted interests"

Improve Social communication

Reduce "Atypical" motor skills

Foster self-determination and sense of identity to promote QoL

Promote participation through client collaboration

Reduce stigma through educating others about Neurodiversity

Models of Disability



Trad vs social models of disability



From deficit to ability



Widely varying skillset

In using the Medical Model of Disability, what approaches do we use?

- **Establish/ restore/ remediate**
 - Remediate sensory processing
 - Establish better communication
 - Improve restricted interests

The Medical Model of Disability is Prevalent in our Research Agenda for Autism

American Occupational Therapy Association. (2017). Research opportunities in the area of people with autism spectrum disorder. *American Journal of Occupational Therapy*, 71, 7102400010. <https://doi.org/10.5014/ajot.2017.712002>

Specific Intervention	Strength of Evidence
Social Skills, Social Communication, Restricted and Repetitive Behaviors, and Play Performance and Leisure Participation	
Group-based social skills training programs in both clinic-based and contextual settings to improve social skills	Strong evidence
PECS to improve social communication	Strong evidence
Joint attention training to improve joint attention	Strong evidence
Activity-based interventions to improve social skills	Area for future research
Computer-based interventions (social skills training, virtual reality, video modeling, and collaborative computer work) to improve social skills	Area for future research
Developmental interventions (e.g., relationship based or floor time) to improve social communication	Area for future research
Parent-mediated interventions (e.g., parent-mediated communication-focused treatment, Autism 1-2-3) and imitation training to improve social communication	Area for future research
Physical activity (kata training and exercise) to decrease restricted and repetitive behaviors	Area for future research
Recess intervention, leisure group, and Social Stories to improve leisure participation	Area for future research
Use of preferred, focused, or restricted special interests to improve social behaviors	Area for future research
Social Stories and peer-mediated interventions to improve social skills	Area for future research
Sensory-motor interventions to improve social communication	Area for future research

In using the Social Model of Disability, what approaches do we use?

- **Create/promote**
 - Match interests and skills to existing opportunities in school, work, home or community
 - Focus on strengths and promote their inclusion in any partnership with a client
- **Modify (compensate/ adapt)**
 - Consider ways to enhance participation without changing the individual
 - Modify the social, physical environment or temporal, virtual contexts
 - Modify the tasks and activities as needed for success
- **Prevent**
 - Consider possible future impacts to health and QoL and develop programs to reduce risk and improve outcomes
- **What approaches do we not use when thinking of the social model of disability?**
 - Establish/ restore/ remediate

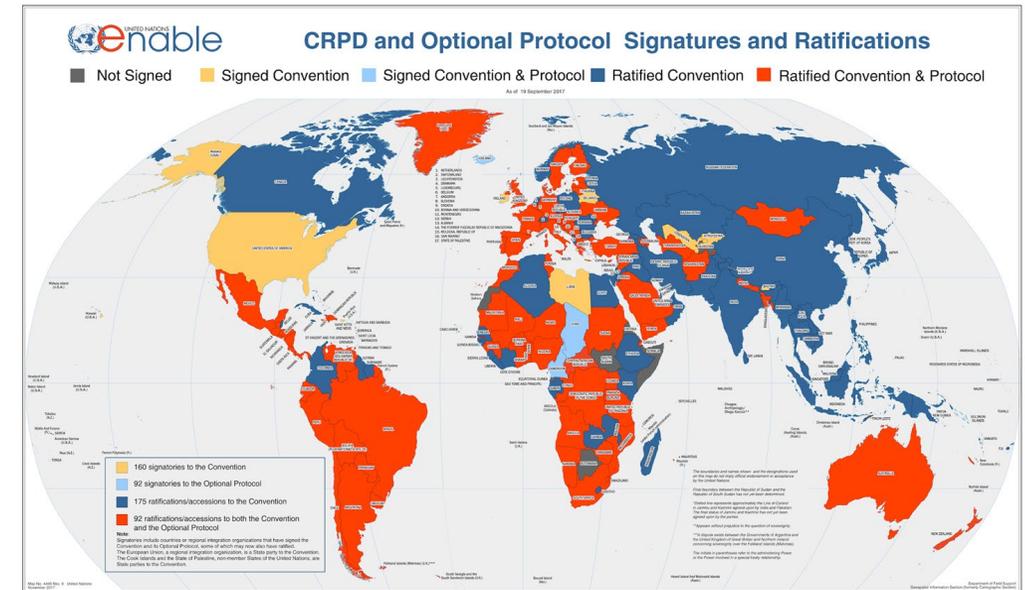


Image by UAA: <http://www.uaa.alaska.edu/accessibility/topic/architecture.cfm>



Moving beyond the Social Model of Disability into the Rights Movement of Disability

- Convention on the Rights of Persons with Disabilities (United Nations), ratified 2006
- Guiding Principles (8):
 - **Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons**
 - Non-discrimination
 - Full and effective participation and inclusion in society
 - **Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity**
 - Equality of opportunity
 - Accessibility
 - Equality between men and women
 - **Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities**



<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Disconnect between what autistic individuals see as important and what society sees as important

- Respect for Neurodiversity and positive attributes of autism
- Recognition of the mental health implications of curative and 'fixing' interventions
- A need to better recognize autism in females & LGBTQ individuals

Supporting Literature

- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2012). Deficit, Difference, or Both? Autism and Neurodiversity. *Developmental Psychology, 49*(1), 59-71. [10.1037/a0028353](https://doi.org/10.1037/a0028353)
- Woods, R. (2017) Exploring how the social model of disability can be reinvigorated for autism: in response to Jonathan Levitt. *Disability & Society, 32*, 7, 1090-1095. doi: [10.1080/09687599.2017.132815737/a0028353](https://doi.org/10.1080/09687599.2017.132815737/a0028353)

Autistic Adults and other Stakeholders Engage Together Research Priorities



Mental Health Priorities

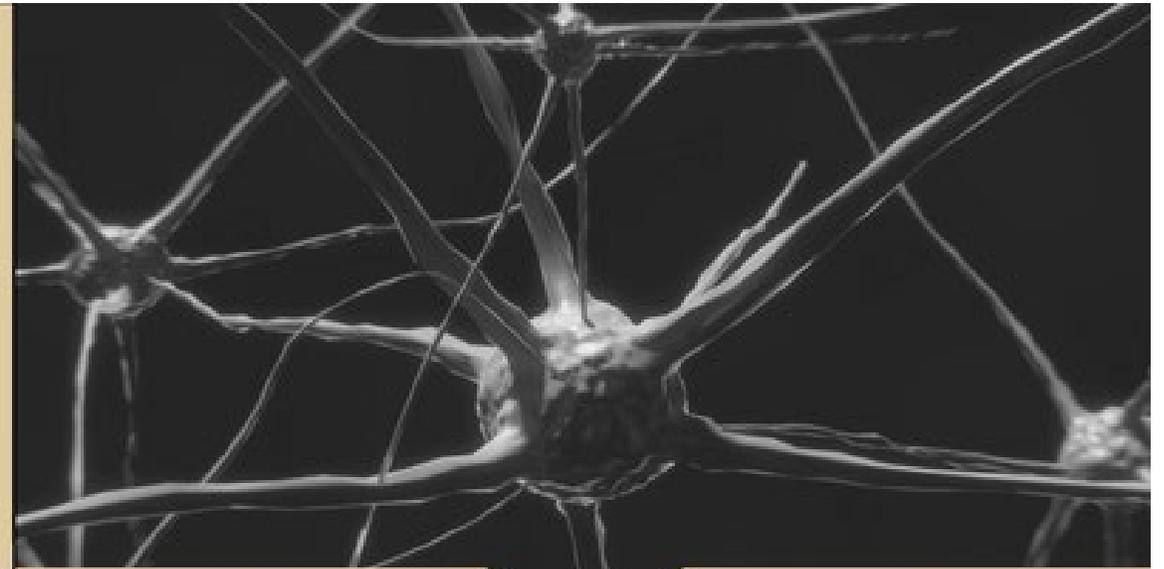
1. Address trauma and stigma through trauma-informed care practices
2. Reduce discrimination and increase sense of identity and opportunity
3. Evaluate non-pharmacological approaches for addressing mental health, including easily accessible, community-based approaches (e.g. yoga, tai-chi, animal-assisted therapy, etc).
4. Reduce exposure to treatments that are demeaning and affect sense of self

Benevides, T.W., Shore, S. and the AASET Community Council (in press). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism (Special Issue in Mental Health)*.doi: 10.1177/1362361320908410

20-37%

HAVE AN ANXIETY
CONDITION

ALMOST 4 TIMES
THE RATE AMONG
SAME AGED
ADULTS



26-30%

HAVE DEPRESSION OR MOOD
DISORDERS

(1) Croen et al. (2015) (2) Roux et al (2017)

Suicide Attempts and Ideation is High

From our data using Medicare claims:

- 4.3% in past year had suicidal ideation.
- 4.1% in past year had hospitalization for suicide attempt or self-inflicted injury

From a recent systematic review in autism, the prevalence of:

- Suicide attempt: 7-47%
- Suicidal ideation: 72% (Hedley & Uljarevic, 2018)
- Hand, B., Benevides, T., Carretta, H.J. (2019). Suicidal ideation and suicide attempts in Medicare-enrolled autistic adults with and without co-occurring intellectual disability. *Journal of Autism and Developmental Disabilities*. <https://doi.org/10.1007/s10803-019-04345-x>
- Hedley & Uljarevic (2018). Systematic review of Suicide in Autism Spectrum Disorder: Current trends and implications. *Current Developmental Disorders Reports*, 5, 65-76.

Table 2 Odds ratios (OR) and 95% confidence intervals (CI) from logistic regression models estimating the odds of at least one medical encounter for suicidal ideation or a suicide attempt during the 48-month study period in Medicare-enrolled autistic adults

	Suicidal ideation		Suicide attempt	
	OR	95% CI	OR	95% CI
Years of age (in 2012)	0.94 [±]	0.93–0.95	0.98 [±]	0.98–0.99
Female	1.14	0.96–1.36	1.12	0.96–1.31
Race				
White (ref)				
Black	0.68 ⁺	0.52–0.88	0.51 [±]	0.40–0.65
Hispanic	0.93	0.62–1.41	1.04	0.72–1.50
Other/unknown	0.78	0.52–1.18	0.78	0.53–1.15
Dually eligible	1.09	0.85–1.40	1.54 [⊥]	1.20–1.98
Bipolar depression	4.51 [±]	3.79–5.37	2.36 [±]	2.03–2.76
Unipolar depression	8.54 [±]	7.12–10.24	1.78 [±]	1.52–2.08
Intellectual disability	0.76 ⁺	0.64–0.90	1.92 [±]	1.64–2.24
Number of Psych hospitalizations ^a	1.20 [±]	1.18–1.23	1.05 [±]	1.03–1.07
Number of Psych ED visits ^a	1.04 [±]	1.03–1.05	1.06 [±]	1.05–1.07

OR odds ratio, CI confidence interval, Psych psychiatric, ED emergency department

⁺p < 0.01, [⊥]p < 0.001, [±]p < 0.0001

Risk Factors for Suicidal Ideation and Suicide Attempts

Social-communication

- Camouflaging

Demographic

- Females

Medical Co-occurring conditions

- Unrelenting depression
- Feeling 'stuck' with frequent negative thoughts
- Overweight/obesity/undereating
- Pain
- PTSD
- Sleep disturbances
- Intellectual disability (lower risk)
- ADHD (lower risk)

- Cassidy et al. (2020). Is Camouflaging Autistic Traits Associated with Suicidal Thoughts and Behaviours? Expanding the Interpersonal Psychological Theory of Suicide in an Undergraduate Student Sample. *Journal of Autism and Developmental Disorders*, online first. <https://doi.org/10.1007/s10803-019-04323-3>
- Hedley & Uljarevic (2018). Systematic review of Suicide in Autism Spectrum Disorder: Current trends and implications. *Current Developmental Disorders Reports*, 5, 65-76.
- McDonnell et al., 2020. An Exploratory Analysis of Predictors of Youth Suicide-Related Behaviors in Autism Spectrum Disorder: Implications for Prevention. *Journal of Autism and Developmental Disorders*, online first. <https://doi.org/10.1007/s10803-019-04320-6>
- South et al. (2020). Unrelenting depression and suicidality in women with autistic traits. *Journal of Autism and Developmental Disorders*, online first. <https://doi.org/10.1007/s10803-019-04324-2>

Priority Interventions to Address Mental Health

Benevides, Shore, et al. (in press). Listening to the autistic voice: Mental health priorities...*Autism*

Table 2. Online Survey Participants Who Endorsed “I would participate” in Mental Health Interventions and Weighted Rank (n=136)

Intervention or Approach	Would Participate, f (%)	Relative Weighted Rank [^]
Art therapy	103 (43.6%)	1
Physical activity/Exercise	99 (41.9%)	2
Animal assisted therapy	116 (49.2%)	3
Music therapy	93 (39.4%)	4
Tai-chi	85 (36%)	5
Occupational therapy	79 (33.5%)	6
Cognitive behavioral therapy	76 (32.2%)	7
Yoga	92 (39.0%)	8
Psychotherapy	74 (31.4%)	9
Suicide prevention/crisis response evaluation	63 (26.7%)	10
Homeopathic medicine	26 (11.0%)	11
Anti-anxiety medications	54 (22.9%)	12
Anti-depressant medications	43 (18.2%)	13
Integrative medicine (complementary/alternative)	28 (11.9%)	14
Tele-medicine	20 (8.5%)	15
Applied behavior analysis	12 (5.1%)	16
Transcranial magnetic stimulation	11 (4.7%) ³⁶	17
Anti-psychotic medications	12 (5.1%)	18

Evidence to Support Preferred Interventions

Benevides, Shore, et al. (in press). Interventions to Address Health Outcomes among Autistic Adults: A Systematic Review. *Autism*.

Evidence Theme	Strength of Evidence	For Improving...	Clinical Implications
Cognitive Behavioral Therapy	Emerging Evidence (6 studies: 2 RCT, 2 quasi, 2 lower)	Anxiety OCD <i>Only for adults without ID</i>	Group or individual CBT, adapted for autistic adults, for 12-108 hours (median 19 hours), delivered weekly for 1-1.5 hours for ~12 weeks.
Mindfulness approaches	Emerging Evidence (2 studies: 1 RCT, 1 quasi)	Depression Anxiety <i>Only for adults without ID</i>	Group mindfulness for 1.5-2.5 hours a session, for 9-12 weeks.

Addressing Suicide

- No peer reviewed evidence with interventions at this time for autistic adults.
- *Brenna Maddox & Susan Jager-Hyman- University of Pennsylvania* – doing a study to adapt the Safety Planning Intervention (SPI) for autistic adults.
- **Crisis Supports Toolkit**
- <https://suicidology.org/wp-content/uploads/2019/07/Autism-Crisis-Supports.pdf>
 - American Association of Suicidology- Autism & Suicide Committee
 - Written by Lisa Morgan, MA

Other Priority Interventions

Benevides, T.W., Shore, S. and the AASET Community Council (in press). Interventions to Address Health Outcomes Among Autistic Adults: A Systematic Review. *Autism*.

No evidence to support these in autistic adults, evidence exists in broader adult literature. Caution should be applied, and inclusion of autistic individuals in adapting these to meet specific individual needs is warranted.

- **Yoga**

- One systematic review and meta-analysis found limited support for individuals with anxiety and depression (Vollbehr et al., 2018)
- One SR and MA found limited support for individuals with PTSD (Cramer, Anheyer, Saha & Dobos, 2018)

- **Tai-chi**

- 5 RCTs found statistically significant improvements in depression outcomes following tai-chi (Solloway et al., 2016)

- **Exercise & Physical Activity**

- PA and exercise is moderately better than placebo or other interventions in non-autistic adults (Cooney et al., 2013).

Areas within OT practice that don't have evidence for work with adults.

You need to be careful about gathering data to support intervention yourself when working with autistic adults.

- Use of art and art-based approaches
- Use of music and music-based approaches
- Use of animals and animal-assisted therapies

CBT and Mindfulness Citations

- Ekman, E., & Hiltunen, A. J. (2015). Modified CBT using visualization for Autism Spectrum Disorder (ASD), anxiety and avoidance behavior--a quasi-experimental open pilot study. *Scand J Psychol*, *56*(6), 641-648. doi:10.1111/sjop.12255
- Hesselmark, E., Plenty, S., & Bejerot, S. (2014). Group cognitive behavioural therapy and group recreational activity for adults with autism spectrum disorders: a preliminary randomized controlled trial. *Autism*, *18*(6), 672-683. doi:10.1177/1362361313493681
- McGillivray, J. A., & Evert, H. T. (2014). Group cognitive behavioural therapy program shows potential in reducing symptoms of depression and stress among young people with ASD. *J Autism Dev Disord*, *44*(8), 2041-2051. doi:10.1007/s10803-014-2087-9
- Russell, A. J., Jassi, A., Fullana, M. A., Mack, H., Johnston, K., Heyman, I., . . . Mataix-Cols, D. (2013). Cognitive behavior therapy for comorbid obsessive-compulsive disorder in high-functioning autism spectrum disorders: a randomized controlled trial. *Depress Anxiety*, *30*(8), 697-708. doi:10.1002/da.22053
- Sizoo, B. B., & Kuiper, E. (2017). Cognitive behavioural therapy and mindfulness based stress reduction may be equally effective in reducing anxiety and depression in adults with autism spectrum disorders. *Res Dev Disabil*, *64*, 47-55. doi:10.1016/j.ridd.2017.03.004
- Spek, A. A., van Ham, N. C., & Nyklicek, I. (2013). Mindfulness-based therapy in adults with an autism spectrum disorder: a randomized controlled trial. *Res Dev Disabil*, *34*(1), 246-253. doi:10.1016/j.ridd.2012.08.009
- Weiss, J. A. & Lunsky, Y. (2010). Group cognitive behaviour therapy for adults with Asperger syndrome and anxiety or mood disorder: a case series. *Clin Psychol Psychother*, *17*(5), 438-446. doi:10.1002/cpp.694

References- Yoga, Tai-Chi, & Exercise

- Cooney GM, Dwan K, Greig CA, Lawlor DA, Rimer J, Waugh FR, McMurdo M, Mead GE. Exercise for depression. *Cochrane Database of Systematic Reviews* 2013, Issue 9. Art. No.: CD004366. DOI: 10.1002/14651858.CD004366.pub6.
- Cramer, H., Anheyer, D., Saha, F.J., & Dobos, G. (2018). Yoga for posttraumatic stress disorder- a systematic review and meta-analyses. *BMS Psychiatry, 18*, 72-
<https://doi.org/10.1186/s12888-018-1650-x>
- Solloway, M. R., Taylor, S. L., Shekelle, P. G., Miake-Lye, I. M., Beroes, J. M., Shanman, R. M., & Hempel, S. (2016). An evidence map of the effect of Tai Chi on health outcomes. *Systematic reviews, 5*(1), 126. doi:10.1186/s13643-016-0300-y
- Vollbehr NK, Bartels-Velthuis AA, Nauta MH, Castelein S, Steenhuis LA, Hoenders HJR, et al. (2018). Hatha yoga for acute, chronic and/or treatment-resistant mood and anxiety disorders: A systematic review and meta-analysis. *PLoS ONE, 13*(10), e0204925.
<https://doi.org/10.1371/journal.pone.0204925>

Addressing other Occupations

- Access to Healthcare
 - Sexuality
- Work

Desired Outcome: Access to Healthcare

1. Increase opportunity to participate in healthcare decisions
2. Understand the impact of the healthcare environment on access
3. Promote skills to increase access to healthcare (e.g. ridesharing, Uber/Lyft skills, use of communication approaches)



Adapting Communication with Healthcare Providers

- Modify the sensory features of the social environment
- Ensure good communication with HCP
- AASPIRE Healthcare Toolkit
- <https://autismandhealth.org/>



The Development and Evaluation of an Online Healthcare Toolkit for Autistic Adults and their Primary Care Providers

Christina Nicolaidis, MD, MPH^{1,2,3}, Dora Raymaker, PhD^{1,3}, Katherine McDonald, PhD^{3,4}, Steven Kapp, MS³, Michael Weiner, MD^{3,5,6,7}, Elesia Ashkenazy, BA³, Martha Gerrity, MD, MPH, PhD^{2,3,8}, Clarissa Kripke, MD^{3,9}, Laura Platt, MD^{1,10}, and Amelia Baggs³

Enhance Ability to Communicate

- **Communication about pain**
 - visual scales, or a body map
- **Ask clear and effective questions**
- **Increase time allowed for communication**

Adapting the Physical Healthcare Environment

- **Modifying the sensory features of the physical environment**
 - Modifying the waiting room to create a quiet area
 - No TV or radio
 - Increasing natural lighting
 - Advocating for waiting rooms without perfumes

Enhancing Transportation

- **Peer-modeling and enhanced transit training**

Beth Pfeiffer, and OT at Temple University is doing a peer-supported travel training study.

Early data suggests that this study is impacting competence and confidence, as well as increased community transportation and mobility.

- Dating?
 - Hygiene?
 - Intimate Relationships?
 - Childbearing ?

Supporting Sexual Wellbeing

- Mismatch between partners needs and one's own sensory needs can impact experiences.
- The experience of sexual arousal may be too intense, or sometimes, not experienced at all
- Anxiety and overstimulation can be a barrier to intimacy

Barnett, Maticka-Tyndale (2015) Qualitative exploration of sexual experiences among adults on the autism spectrum: Implications for sex education. *Perspectives on Sexual & Reproductive Health*, 47, 171-179.

M, a 39-year-old heterosexual woman, described her experience this way:

“My sensory processing differences make some kinds of touch too intense or even physically painful. I sometimes have trouble recognizing this in real time while it’s happening and/or communicating this to a partner. Sometimes I will realize that I’ve been gritting my teeth and enduring something unpleasant for five minutes or so without noticing it, before I get my act together to push someone’s hand away or ask for a different kind of touch.”

Occupational Therapy's Role

- Sexual education
 - Discuss normalcy of experiences being different
 - Encourage exploration of how sensation may change during solitary or dyadic sexual experience.
- Modify the Task (for dyadic)
 - Negotiation of when, how, and what is appropriate between partners - "literal declaration"- Barnett et al 2015
 - Ensure communication occurs and partners agree (include written or text based communication)
 - For heightened sensitivity, can reduce skin-to-skin contact with different positioning
- Ensure client receives trauma informed care for any negative or abusive experiences

References for Sexual Experiences and Autism

Barnett, J. P., & Maticka-Tyndale, E. (2015). Qualitative Exploration of Sexual Experiences Among Adults on the Autism Spectrum: Implications for Sex Education. *Perspect Sex Reprod Health*, 47(4), 171-179. doi:10.1363/47e5715

Byers, E. S., Nichols, S., Voyer, S. D., & Reilly, G. (2013). Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship. *Autism*, 17(4), 418-433. doi:10.1177/1362361311431950

Dewinter, J. Graaf, H., Begeer, S. (2017). Sexual orientation, gender identity, and romantic relationships in adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47, 2927-2934.

Pregnancy & Childbearing

- Hypersensitivity to sound, light and touch may impact experience
- One woman reported that sensory experiences became more extreme during pregnancy, especially around 25 weeks.
- Rogers, Lepherd, Ganguly & Jacob-Rogers (2017)

First person experiences

As well as the hallucinations, Melanie, who had some strong sensory experiences normally during her life, found that they were exacerbated by the pregnancy.

Sometimes I worried that I was going mad. Logically, I would tell myself that this is just like the Asperger's probably and it's just gone bananas, but I would still be anxious about it. And, the thing is, I seemed to be able to cope with it, until people started to touch me, and seemed to be just the extra-sensory input that seemed to trip another level of stress.

I found that I coped with the sensations about the birthing quite well but I didn't cope with people touching with me in any way, shape or form. I found it really difficult when the midwives did an examination of the cervix to see how dilated I was. I couldn't stop screaming and just about jumped off the bed.

- Rogers, Lephherd, Ganguly & Jacob-Rogers (2017)

OT Role in Pregnancy & Childbearing

- Presume competence.
- Education for women about ways that body may change, including sensorily
- Education of medical professionals about the experiences
- Modify the environment: seeking alternative environments besides hospitals for birth
- Possible discussion of coping and stress-reduction techniques for procedures that must occur during pregnancy & childbirth

Sensory Experiences and Childbearing References

- Gardner, M., Suplee, P. D., Bloch, J., & Lecks, K. (2016). Exploratory Study of Childbearing Experiences of Women With Asperger Syndrome. *Nurs Womens Health, 20*(1), 28-37.
doi:10.1016/j.nwh.2015.12.001
- Rogers, C., Lepherd, L., Ganguly, R., & Jacob-Rogers, S. (2017). Perinatal issues for women with high functioning autism spectrum disorder. *Women Birth, 30*(2), e89-e95.
doi:10.1016/j.wombi.2016.09.009

Desired Outcome: Meaningful Work and Employment in Areas of Interest

- Social model of disability- work environments may impact participation in work occupations
- Identifying a person's strengths and interests is key
- Promoting self-advocacy, or the ability to advocate for needed accommodations, is essential
 - Work from home if environment is too distracting or anxiety producing
 - Opportunities to communicate by preferred methods
 - Chances for feedback and support
 - Use of evidence-based approaches for supporting work outcomes

Adapting the Environment: Use of Technology to Improve Work Outcomes (n=12 studies)

Sub-Theme	Number of Articles	Strength of Evidence
Video Modeling	6	Evidence-Based
Audio/ Visual Prompting	3	Insufficient Evidence
Interactive Technology	3	Insufficient Evidence

Curran, K., Huntington, J., Siefert, A., Slog, K., Stromer, M. and Toussaint, K (2015). "Making It Work: Individuals with Autism Spectrum Disorder and Adaptations for Successful Employment". *Collaborative Research and Evidence shared Among Therapists and Educators (CREATE Day)*. Paper 41. <https://jdc.jefferson.edu/createday/41> . Mentor: Dr. Teal Benevides⁵⁹

Use of Technology: Video Modeling (n=6 studies)



**Creating a video for video modeling:
VideoTote software
(n=1)¹²
<https://youtu.be/-8H7R6Albok>**



**Point of view video modeling
(n=4)^{1, 3, 7, 39}**

Curran, K., Huntington, J., Siefert, A., Slog, K., Stomer, M. and Toussaint, K (2015).

Use of Technology: Video Modeling (n=6 studies)

Timing of Video Exposure:

- Viewed at work site, **immediately prior to, or during** work task
(n = 5)^{1, 3, 7, 12, 21}
- Viewed **prior to arrival** at workplace (n = 2)^{12, 39}

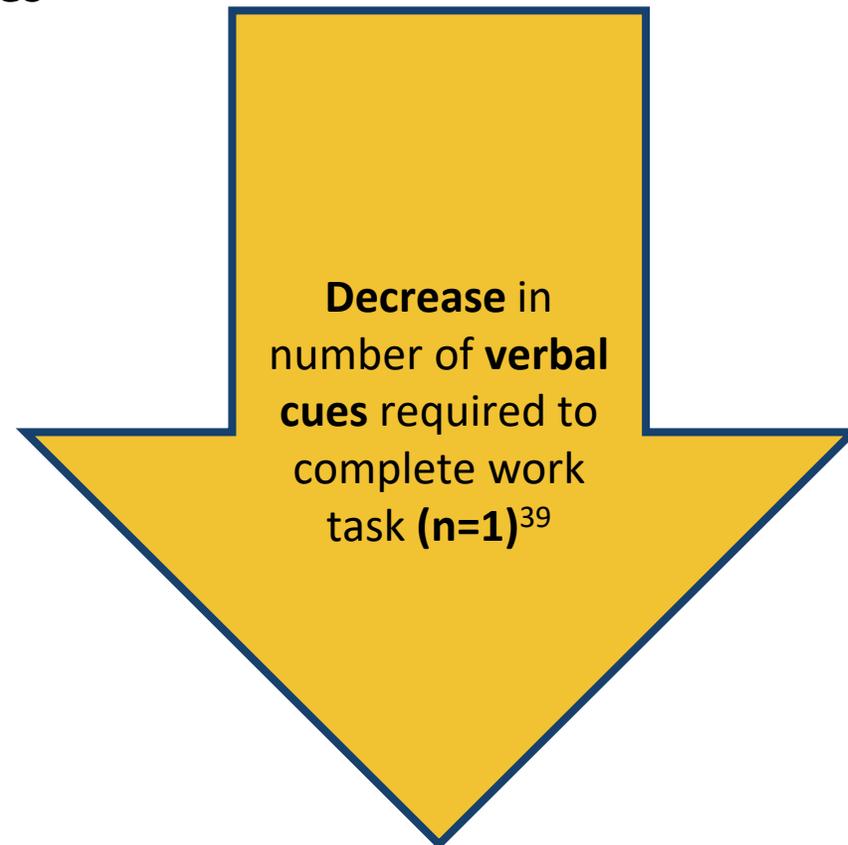
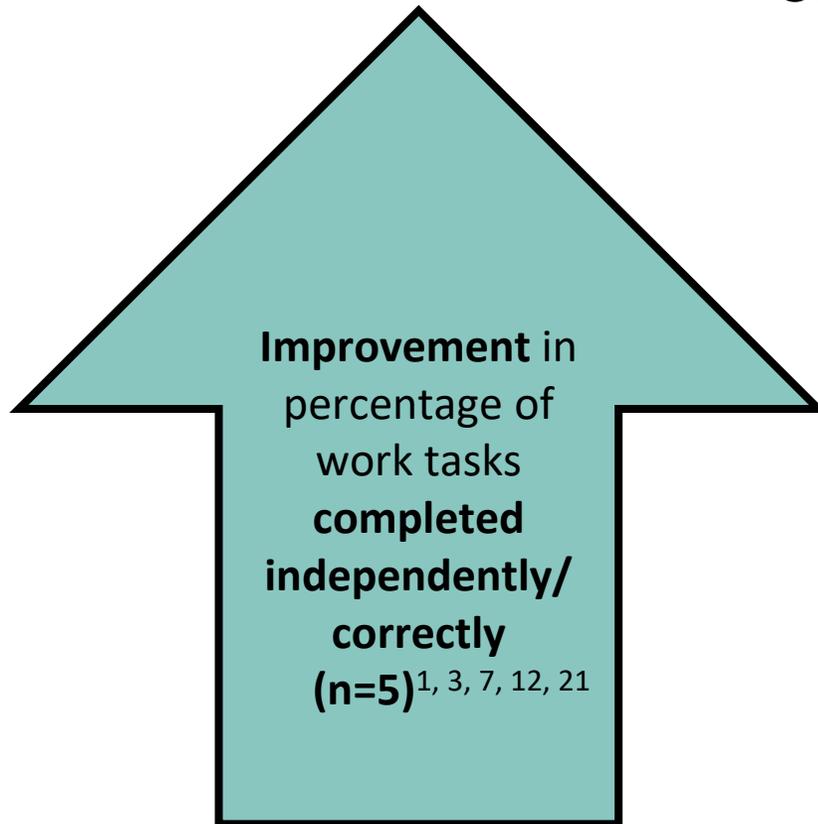
Actors in Video:

- **Familiar** to the participant and **similar in age** (n = 1)²¹

Theme: Use of Technology

Video Modeling (n=6 studies)

Outcomes



Theme: Multifaceted Approach (n=10 articles)

- Adaptations in work environments have multiple dimensions and the **effects of each cannot be isolated in outcome measures**
 - Implement variety of instruction/training approaches OR
 - Adapt range of environments/contexts OR
 - Address multiple activities within work area of occupation

Sub Theme	Number of Articles	Level of Evidence
Formal Programs	4	Evidence-Based Practice
Informal Programs	6	Insufficient Evidence

Formal vs. Informal Programs

Formal	Informal
<ul style="list-style-type: none">● Implemented in multiple sites● Defined protocol● Multi-component interventions/ adaptations	<ul style="list-style-type: none">● May or may not have a defined protocol● Separate components, the effects of which cannot be isolated

Theme: Multifaceted Approach Formal Programs (n=4 articles)

Article	Level of Evidence	Quality	Program
Strickland, Coles, & Southern, 2013 ³⁶	I	High	JobTIPS plus simulated interview training
Wehman et al., 2014 ⁴³	I	High	Project SEARCH plus ASD supports
Ham, McDonough, Molinelli, Schall, & Wehman, 2014 ¹⁷	IV	Low	Project SEARCH plus ASD Supports
Wehman, Schall, McDonough, Molinelli, Riehle, Ham & Thiss, 2013 ⁴²	IV	Low	Project SEARCH plus ASD supports



Theme: Multifaceted Approach

Formal Programs - JobTIPS (n=1)

JobTIPS is an established online **multimedia employment training** program offering 5 sections* to guide the individual with ASD through:³⁶

- Determining Career Interests
- Finding a Job
- Getting a Job
- Keeping a Job
- Other Job Topics



do2learn.blogspot.com

*Subsections added to target interview skills during this study

JobTIPS **combined with virtual reality** interview training:³⁶

- Remote 30 minute practice session using **avatars** online
- Direct, positive **feedback** + explicit **instruction** for improvement
- Repeated **rehearsal**

Theme: Multifaceted Approach, Formal Programs (n=4)

Setting:

- Programs were embedded into an actual workplace (n=3)^{17, 42, 43}

Impact of Programs:

- Improvement in social areas related to employment (n=4)^{17, 36, 42, 43}
- Decrease in frequency of challenging work behaviors (n=3)^{17, 42, 43}
- Participants secured employment or maintained current job following intervention (n=3)^{17, 42, 43}
- Participants maintained outcomes at time of follow-up (3 months - 2 years) (n=2)^{17, 43}

References- Work Outcomes

- [1] Alexander, J. L., Ayres, K. M., Smith, K. A., Shepley, S. B., & Mataras, T. K. (2013). Using video modeling on an iPad to teach generalized matching on a sorting mail task to adolescents with autism. *Research in Autism Spectrum Disorders*, 7(11), 1346-1357.
- [3] Allen, K. D., Wallace, D. P., Greene, D. J., Bowen, S. L., & Burke, R. V. (2010). Community-based vocational instruction using videotaped modeling for young adults with autism spectrum disorders performing in air-inflated mascots. *Focus on Autism and Other Developmental Disabilities*, 25(3), 186-192.
- [7] Berezna, S., Ayres, K. M., Mechling, L. C., & Alexander, J. L. (2012). Video self-prompting and mobile technology to increase daily living and vocational independence for students with autism spectrum disorders. *Journal of Developmental and Physical Disabilities*, 24(3), 269-285.
- [12] Burke, R.V., Allen, K.D., Howard, M.R., Downey, D., Matz, M.G., & Bowen, S.L. (2013). Tablet-based video modeling and prompting in the workplace for individuals with autism. *Journal of Vocational Rehabilitation*, 38(1), 1-14.
- [17] Ham, W., McDonough, J., Molinelli, A., Schall, C., & Wehman, P. (2014). Employment supports for young adults with autism spectrum disorder: Two case studies. *Journal of Vocational Rehabilitation*, 40(2), 117-124.
- [21] Kellems, R. O., & Morningstar, M. E. (2012). Using video modeling delivered through iPods to teach vocational tasks to young adults with autism spectrum disorders. *Career Development for Exceptional Individuals*, 35(3), 155-167.
- [36] Strickland, D., Coles, C., & Southern, L. (2013). JobTIPS: A transition to employment program for individuals with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 43(10), 2472-2483.
- [39] Van Laarhoven, T., Winiarski, L., Blood, E., & Chan, J. M. (2012). Maintaining vocational skills of individuals with autism and developmental disabilities through video modeling. *Education and Training in Autism and Developmental Disabilities*, 47(4), 447-461.
- [42] Wehman, P., Schall, C., McDonough, J., Molinelli, A., Riehle, E., Ham, W., & Thiss, W. R. (2013). Project SEARCH for youth with autism spectrum disorders: Increasing competitive employment on transition from high school. *Journal of Positive Behavior Interventions*, 15(3), 144-155
- [43] Wehman, P., Schall, C., McDonough, J., Kregel, J., Brooke, V., Molinelli, A., . . . Thiss, W. (2014). Competitive employment for youth with autism spectrum disorders: Early results from a randomized clinical trial. *Journal of Autism & Developmental Disorders*, 44(3), 487-500.

Summary- Best Practices

- **Promote social-model approaches over medical-model approaches**
 - Create/promote
 - Modify (compensate/ adapt)
 - Prevent
 - Advocate
- **Use principles of autistic alliance**
 - Presume competence, Use respectful language, Foster communication
- **Focus on desired (client-identified) preferred outcomes and approaches**
 - Emphasize strengths and incorporate into treatment
 - Emphasize self-determination and choices in appropriate adult occupations
 - Promote self-esteem, identity
 - Enhance mental and physical health

Objectives

At the conclusion of this presentation, learners will:

1. **Identify** 3 specific actions that support authentic alliance with autistic adults.
2. **Discuss** opportunities for promoting increased quality of life and occupational performance, aligned with priorities that are identified by this population.
3. **Promote** practice with individuals, groups, and populations through case evaluations.
4. **Interpret** evidence that supports authentic alliance with autistic adults.

Questions!

Thank you! Feel free to contact us for any references or additional thoughts/questions/ concerns:

tbenevides@augusta.edu

sshore@adepi.edu

AASET Studies are in-press and will be available in the next month. Published in the journal *Autism*.

- Shore, S., Benevides, T.W. and AASET Community Council. Engagement and Compensation Guide, Ver. December 2018. Available at: <https://www.pcori.org/sites/default/files/AASET-Engagement-Guide-122018.pdf>
- Benevides, T.W., Shore, S. and the AASET Community Council (in press). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism (Special Issue in Mental Health)*.doi: 10.1177/1362361320908410
- Benevides, T.W., Shore, S. and the AASET Community Council (in press). Interventions to Address Health Outcomes Among Autistic Adults: A Systematic Review. *Autism*.